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COMMISSION ON HUMAN RIGHTS

Sub-Commission on Prevention of
Discrimination and Protection
of Minorities
Working Group on Indigenous Populations
Sixteenth session
27-31 July 1998

PROVISIONAL AGENDA

1. Election of officers.

2. Adoption of the agenda.

3. Organization of the work of the session.

4. Review of developments pertaining to the promotion and protection of human rights and fundamental freedoms of indigenous people: general statements.

5. Principal theme: Indigenous peoples - education and language.

6. Indigenous peoples and health: follow up and recent developments.

7. Standard-setting activities: evolution of standards concerning the rights of indigenous people:

   (a) Possible future standard-setting activities, including principles and guidelines for private sector energy and mining concerns.

8. Consideration of the final report of the Special Rapporteur of the Sub-Commission on treaties, agreements and other constructive arrangements between States and indigenous populations.

9. Consideration of the working paper of the Special Rapporteur of the Sub-Commission on indigenous peoples and their relationship to land.

GE.98-12732 (E)

10. Consideration of the establishment of a permanent forum for indigenous people.

11. International Decade of the World's Indigenous People:

    (a) Voluntary Fund for the International Decade of the World's Indigenous People;

    (b) Activities and report of the Advisory Group;

    (c) Preparations for the mid-point review of the Decade.

12. Other matters:

    (a) Meeting and seminars;

    (b) Voluntary Fund for Indigenous Populations.

13. Adoption of the report of the Working Group on its sixteenth session.

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27 - 31 July 1998
Item 5 of the provisional agenda

REVIEW OF DEVELOPMENTS PERTAINING TO THE PROMOTION AND PROTECTION OF HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS OF INDIGENOUS PEOPLE: INDIGENOUS PEOPLES - EDUCATION AND LANGUAGE

Note by the secretariat

Information received from intergovernmental organizations and indigenous peoples

1. In its resolution 1982/34 of 7 May 1982, entitled "study of the problem of discrimination against indigenous population", the Economic and Social Council authorized the Sub-Commission on Prevention of Discrimination and Protection of Minorities to establish annually a working group on indigenous populations to review developments pertaining to the promotion and protection of the human rights and fundamental freedoms of indigenous populations, together with information requested annually by the Secretary-General, and to give special attention to the evolution of standards concerning the rights of indigenous populations.

2. In its resolution 1997/14 of 22 August 1997, entitled "Working Group on Indigenous Populations", the Sub-Commission requested the Secretary-General to transmit the report of the Working Group to indigenous intergovernmental, and non-governmental organizations and to invite them to provide information, in particular on matters relating to indigenous peoples: "education and language". The Commission on Human Rights, in its resolution 1998/13 of 9 April 1998, urged the Working Group to continue its comprehensive review of developments and welcomed the proposal to highlight the question of indigenous education and language. The present document contains information in relation to item 5 of the provisional agenda.

UNITED NATIONS EDUCATION, SCIENTIFIC AND CULTURAL ORGANIZATION

[Original: French]
[12 May 1998]

METHODOLOGICAL NOTES ON LINGUISTIC REFORM TO PROMOTE INDIGENOUS LANGUAGES

Why should literacy be taught in indigenous languages?

1. It is now well established that early learning normally takes place through the medium of the mother tongue up to the operational stage, and one of the reasons why today's students have been falling behind or failing in many education systems is that this fact has been disregarded. The mother tongue is what enables children to "take off" intellectually once they start school. It provides a basic stability, without which children fail to develop, and it enables children to put their thoughts into words and to integrate harmoniously with the world around them. Children feel comfortable in their mother tongue, as they do in their parents' arms, and by denying them the opportunity to use this familiar linguistic support, so appropriate to their basic needs of self-expression and creativity, the school at once begins to hold them back.

2. In the light of this reality, there is no doubt whatsoever that, in the coming years, indigenous languages will become central to all the major educational reforms that are being undertaken virtually throughout the world. Such near-unanimity is no accident, nor is it due only to the current convergence in cultural policies; it is rather the product of a new educational awareness fostered by the emergence of educational methodology as a scientifically based discipline and by the strong influence on education of applied psychology, which has underlined how vital the mother tongue is to the continuity of children's psychomotor, affective and cognitive development.

How should literacy be taught in indigenous languages?

3. The following is a broad outline of a functional, flexible programme, describing the specific tasks to be undertaken in countries that are embarking upon, or wish to embark upon linguistic reform based on the use of one or more indigenous languages for literacy teaching in a formal educational context.

A. Design and prepare a blueprint for the project as a whole

4. Implementing linguistic reform requires not merely political will but also a technically and methodologically rigorous approach. It is not a random, haphazard undertaking but has conditions, premises and rules that should be set forth in a blueprint forming the scientific basis for the project. The blueprint should:

(a) Clearly formulate the underlying linguistic and socio linguistic premises, i.e. answer the following questions:

- Which indigenous language(s) will be used in the educational programmes? (This is the problem of choosing the languages of instruction.)
- What educational status will the indigenous languages have, i.e. will they be the medium for teaching and/or a subject to be taught?
- What status will the non-mother tongue previously used have (e.g. in Africa, English, French, Portuguese, etc)? Will that status be total or partial? (This is the problem of defining explicitly the educational status of the languages of instruction.)

(b) Identify which parameters are under the control of those promoting linguistic reform and which are not:

- Parameters that may affect the children's situation (the indigenous language is not always the mother tongue of all the children in the same school).
- Parameters affecting the teachers' situation (i.e. the problem of linguistic status in relation to the languages of instruction used in multilingual countries).

(c) Prepare a plan of action taking the above-mentioned points into account: the programme contents should be devised, formulated, tested, evaluated and adjusted on an ongoing basis during the various stages of the reform.

5. A project aimed at providing initial literacy in indigenous languages generally comprises the following four distinct phases: an exploratory research phase, an experimental phase, a further experimentation phase and (optionally) a generalization phase.

6. This procedure, it should be noted, is rather theoretical and its general applicability is considerably limited by the multiplicity of national situations and the specific objectives of each country. Nevertheless, even though the stages are not always explicitly described, they refer to essential activities which cannot be omitted with impunity.

B. Begin training agents of the reform (teachers, future teachers and future teacher trainers)

Training teachers and future teachers

7. Specifically, teachers must be trained to teach an indigenous language using that indigenous language. In addition to a course in applied linguistics that will enable them to write the language correctly and understand its internal structure, they will also take an education course that should focus essentially on the teaching of those subjects to be taught in the indigenous language. Teachers will be trained to give priority to

aspects of the national culture as sources of inspiration for educational activities. Educational psychology training will be based on concrete situations encountered in schools.

Training future teacher trainers

8. The linguistic, methodological and educational psychology training given to teacher trainers will cover in greater depth points they will already have studied in their own professional training as teachers. In addition, it will be necessary to:

- Provide comprehensive instruction on the sociolinguistic situations to be found in their own country or within the region;
- Give them the ability to explain to teachers and future teachers the methodology and content of textbooks written about and in indigenous languages;
- Train them in a coherent language teaching methodology, within a context of educational bilingualism (indigenous language, national language, foreign language).

9. Generally speaking, reform agents' participation in limited linguistic and educational psychology research will be planned and organized as an integral part of their professional training.

10. One of the most important lessons to be learned from the various projects geared towards the use of indigenous languages as the medium for literacy in schools is that the training of agents and teachers cannot be separated from the process of making them aware of the rationale underlying the reform. To ignore or deliberately deny this fact is to build on sand.

C. Set up structures for the design, production and dissemination of indigenous language teaching materials produced in indigenous languages

Design

11. Before designing new textbooks, any that already exist in the language, even abroad, must be listed and examined. It may be possible to revise and update some of them and bring them back into use. This is an educational question.

Production

12. A timetable for producing teaching materials in the indigenous languages should be drawn up and adhered to. Adherence to the timetable will depend on the effective recruitment of a sufficient number of staff (typing pool, graphic artists, etc.). This is a technical question.

Dissemination

13. Dissemination is a key issue. Experience shows that if teachers do not receive new textbooks and programmes in good time and in sufficient quantities, they will quickly revert to the traditional programmes they can already handle. Smooth dissemination depends on the measures taken in the areas of storage and transport. This is an administrative problem.

14. The ability to produce basic teaching materials (teachers' guides and students' textbooks in the core subjects) is a major factor influencing the effectiveness of literacy teaching in indigenous languages. It is naturally desirable for the educational institution itself to take responsibility not only for the design of such materials (subcontracting if necessary) but also for their production and dissemination. If this job is to be done well, staff, premises and equipment requirements must be taken into account.

D. Carry out a study of the legal, administrative, financial and technical framework for the effective implementation and development of the reform

15. What is specifically needed is:

(a) Support for literacy teaching in indigenous languages in clear, comprehensive statements by the authorities;

(b) An unequivocal definition of the administrative status of the researcher, teachers and pupils taking part in the reform, in relation to the existing system (updating of tests and competitive examinations, modalities of teacher recruitment, etc.);

(c) "Bridges" between the reformed system and other levels of education such as secondary and technical;

(d) The specific involvement in the linguistic reform project not only of the full range of services of the ministries responsible for national education, and of local administrations, but also of the services of other ministries and national agencies (universities, private education, departmental managers of the Ministry of the Interior, trade unions, religious groups, etc.);

(e) Identification of essential sources of financing and, if necessary, the definition of modalities for technical cooperation with other States or specialized international agencies;

(f) Effective links between linguistic and psychological research services and services providing training for teachers and for teacher trainers.

16. The need to set indigenous language literacy teaching within a well-defined legal, administrative, financial and technical framework would appear to be self-evident. Experience shows, however, that reforms are often undertaken in the field without prior definition of such an institutional framework. The resulting lack of clarity gives rise to numerous teething

troubles and constant disagreement. The lack of a legal framework, for example, is nearly always perceived by the various partners in the reform as a sign of more or less overt governmental indifference to the project. One very natural result is that neither teachers nor the general population feel motivated. It is not unreasonable, then, to view the existence of a formal frame of reference as the cornerstone of any policy aimed at raising national awareness of the reform.

Conclusion

17. As can be seen, the introduction of indigenous languages into the school curriculum is no random venture. The project is perfectly controllable to the extent that an initial programme, designed and developed with care and with due regard to the country's specific situation, is made the blueprint for the scheme.

18. The programme must be both functional and flexible. Its functionality derives from the fact that it is an instrument of direct intervention and an operational tool designed to set in motion, at the desired time and pace, the various engines of linguistic reform. Its flexibility derives from the fact that it must provide adaptable guidelines that can be updated periodically, for example at the end of each year, in order to take account of the constraints imposed by, inter alia, limited financial and human resources.

19. Put simply, the existence of an initial programme enables a linguistic reform project manager to see where to begin and how to stay on course.

20. An analysis in good faith of the underlying cause of the failure of past reforms invariably shows that realistic initial programming and blueprints either were not adhered to or were simply non-existent. The suitability of indigenous languages as media for literacy or teaching is not in doubt.

FEDERATION OF INDEPENDENT ABORIGINAL EDUCATION PROVIDERS

[Original: English]
[6 May 1998]

INDIGENOUS PEOPLES AND OUR RIGHT TO AN INDEPENDENT INDIGENOUS EDUCATION SYSTEM

By Jack Beetson, President, Federation of Independent Aboriginal Education Providers Ltd., Australia

1. The Federation of Independent Aboriginal Education Providers (FIAEP) is a national agency which officially formed in 1996 to promote the rights, interests and development of the independent Aboriginal community-controlled adult education sector within Australia. FIAEP aims to provide Aboriginal education, not education for Aborigines, and fundamental to our work is the principle that education is a means to self-determination. We present the following points relevant to the forthcoming WGIP deliberations on the theme of education. Our comments relate mainly to articles 3, 12, 13, 14 and 15 of the draft United Nations declaration on the rights of indigenous peoples.

2. Firstly, indigenous education reflects and maintains the cultures, values and knowledge of our peoples - peoples who have a history going back at least 50,000 years, peoples who have survived a genocide invasion of our lands. Our knowledge, our cultures and our languages belong to us, they are what makes us who we are. Indigenous education is part of passing this knowledge on to future generations. Of course we also need to learn about the dominant non-indigenous cultures, but we assert our right to learn in our own ways, at our own pace, in institutions that we own and control. Articles 12-14 of the draft declaration regarding our cultural, spiritual and linguistic identity, and article 15, regarding education, deal explicitly with this right. Articles 12 and 13 express our right to practise and revitalize our cultural traditions, our right to protect our sacred sites, and our cultural and intellectual property rights. Article 14 recognizes our right to develop and transmit to future generations our histories, languages, oral traditions, philosophies and writing systems and calls on States to take action to protect these rights. To deny someone's identity is to deny them their right to learn from within their own experiences, their own culture; their right to read the world, as Freire called it, with one's own framework, rather than one imposed from outside.

3. Secondly, because of this, indigenous education and indigenous self-determination cannot be separated. Genuine indigenous education only happens when indigenous people have real power over the education process. Article 3 of the draft declaration states very simply, in the same terms exactly as those of the Charter, our right to self-determination. This means we have rights to freely determine our own development paths and, as indigenous peoples, our needs and aspirations do not always coincide with the development framework pursued by the dominant society. However, we not only have a right, but we have a responsibility to determine economic, social and cultural development strategies which strengthen our distinct identities.

4. Thirdly, indigenous education is firmly based in the real day-to-day experiences of our students and our communities. If it were not for us, for the programmes we provide, many of our students would not only not have an education, they would not have a life. Landlessness, unemployment, poverty, poor housing, appalling health standards, alcohol and drug abuse, imprisonment, violence - these are day-to-day realities for the vast majority of indigenous peoples. The "mainstream", or the non-indigenous education system, has failed us, as indigenous peoples; it has been part of the problem. Indigenous education is part of the solution.

5. Non-indigenous education systems have been deeply implicated in the systematic efforts to take from us our languages, our cultures and our children, and therefore our essential identities as indigenous peoples. In Australia, the 1989 Royal Commission into Aboriginal Deaths in Custody concluded that the mainstream education systems had been either unable or unwilling to accommodate many of the values, attitudes, codes and institutions of indigenous society. The Commissioner expressed his strong support for "the expressed desire of indigenous people for education and training which will support their aspirations for self-determination", and called for "a concerted and comprehensive commitment to the development of appropriate education and training programmes which are accessible, both geographically and culturally, to the greatest number of indigenous people possible". It specifically recommended that the independent Aboriginal community-controlled colleges be given full support by governments (Rec. 298).

6. Nearly a decade has passed since the Royal Commission began its inquiries. In that time, neither the rates of imprisonment nor the number of deaths has decreased. Rates of imprisonment are increasing, not decreasing, and last year, Amnesty International reported that another 21 indigenous people died in custody or during police operations. FIAEP research into the extent to which the specific recommendations of the Royal Commission have been implemented demonstrates beyond doubt that non-indigenous Australia continues to base its own systems of education and government on the denial of our communities' fundamental rights to exist as distinct peoples, governing and educating themselves.

7. Fourthly, we assert our right to be treated as a separate and independent sector of the Nation State education system. We have a distinct indigenous identity, and we have a right to a distinct indigenous education. We assert our rights as indigenous peoples to have access to the resources with which to develop our own education systems. This right is clearly expressed in article 15 of the draft declaration. It is this right that my own organization expresses in practice. This is what we mean when we say "Aboriginal education is not the same as education for Aborigines". Public policy on Aboriginal education in Australia still avoids the question of indigenous peoples' special rights in this area, focusing instead on issues such as individual disadvantage, access and equity.

8. To summarize, we want choice for our people, a choice which is central to our self-determination, an opportunity to study and to learn in our own ways, in our families, our communities and our organizations, as an alternative to the mainstream government and non-indigenous-controlled education systems.

9. We have a right to more than self-management, by which the State usually means positions of some power and influence within their own education systems and the other systems of non-indigenous Australia. When we step outside those mainstream systems, we are marginalized. There is an urgent need for Governments to recognize and accept the concept of co-existence whereby we live together peacefully whilst retaining our distinct education systems and institutions.

10. In 1994 indigenous peoples accepted the current text of the draft declaration as the final expression of the minimum international standards for the protection and promotion of our fundamental rights. Today we do not enjoy our full human rights - our rights to life, to health, to freedom, to maintain and practise our culture, to speak in our own languages, to live on our own lands. The reason is that these rights are still not recognized and understood by non-indigenous systems of governance.

NEW SOUTH WALES/AUSTRALIAN CAPITAL TERRITORY ABORIGINAL AND TORRES STRAIT ISLANDER HIGHER EDUCATION NETWORK

[Original: English]
[14 May 1998]

Indigenous education and research

1. The present note will address the issue of research in institutions of higher education and the rights of indigenous people. Research ethics as they apply in institutions of higher education generally focus on human ethics and animal experimentation. There has been no substantial approach to developing ethics policies which have as their central consideration research with indigenous people. Global examinations of the research related to indigenous people conducted by universities and other research bodies uncovers situations where the rights of indigenous people are often infringed or ignored in the process of investigation.

2. Indigenous people are considered, in some academic domains, to be a useful and available source of information and knowledge which can be accessed by those engaged in research. The different disciplines who use the indigenous populations for such pursuits include pure science, human genetics, biology, social science, anthropology, archaeology, pre-history, engineering, medicine, environmental studies and education. Exploitation of indigenous people is occurring through the research conducted by institutions of higher education worldwide. This exploitation can be most obvious in invasive human experimentation and less overt, but also damaging, in the removal of indigenous knowledge from the control of indigenous peoples.

3. The issue of ownership of knowledge is central to research in education where indigenous adults and children are used as the subjects for an extensive range of data-gathering projects. These can range from literacy to learning styles. Indigenous people can be placed under cultural stress in the acquisition of literacy. It is essential that all the peoples of the world have the right to learn to communicate in the various languages of the globe, however, it is generally the case that indigenous people have to acquire

literacy in languages other than our own. This impacts on how our knowledge and processes for education are recognized amongst our communities and those of different, sometimes dominant cultures. Owning indigenous knowledge in the process of education research can be a difficult and delicate matter. There is, however, the matter of historical exploitation and a continuing process of colonization. This will only be resolved when ownership of knowledge is retained by indigenous people. Issues of access, control and power relations in the sharing of knowledge between indigenous and non-indigenous people must be dealt with to ensure ethical practice in research involving indigenous people.

4. Linda Tuhiwai Smith, from the University of Auckland, in her critique of western research points out that Pakeha (non-Maori) research brings to bear, on any study of Maori, a cultural orientation, a set of values, a different conceptualization of such things as time, space and subjectivity, different and competing theories of knowledge, new subsets of English language and power structures. In Australia, Aboriginal and Torres Strait Islander peoples are also reconstructing the research frameworks. Many indigenous people involved in this process of reconstruction look to "Aboriginal terms of reference". There is a structural difference between indigenous and non-indigenous researchers in current research practice in Australia. Darryl Kickett believes the difference is because "within the Aboriginal world the value system places emphasis on obligations and relationships within and between family and the non-human world".

5. Indigenous people are bound by who has the right to speak, investigate or research on behalf of others. Thus, as indigenous people we want to set boundaries on our engagement in research with non-indigenous researchers. This is not to say we wish to stop all research. We need to support non-indigenous researchers who are self-critical and who work with indigenous people to "ensure empowerment, and their own degrees of dis-empowerment, [by moving] through the dominant culture to effect change".

6. Amongst indigenous Australian people the spread of knowledge carries with it, at times, many restrictions and there cannot be any compromise on these. To do so may mean alienation or punishment from the aggrieved individuals or group, which would be of greater personal and community cost than would be any advantages obtained from revealing the knowledge. Thus we come to the issue of "what is knowledge?". In tertiary institutions knowledge is regarded as a product. It is extracted, packaged and delivered to particular groups for consumption. The notion that all knowledge from (indigenous) groups should be accessible and available for interpretation has only been questioned in recent times. Previously, the right to ownership of indigenous knowledge had been wrenched away and stored with individuals and institutions who claim a right on the packaging and distribution of that knowledge. This often overrides the ownership rights of those who are or were the source of that knowledge.

7. In Aboriginal societies access to knowledge is determined from the role each person has within that grouping. This is supported by the structure of education where learning is a lifelong process not dictated by institutions, but by the people and the community, and for that process to be given its proper place there must be recognition of the different knowledge bases. All

of the complexities with which Indigenous knowledge is transferred in Aboriginal societies goes beyond mere subject matter and lies within who we are as a people. It forms our identity.

8. We all need to value difference and incorporate that into the dominant cultural practice in research. The guiding principles for conducting research are:

(a) Indigenous peoples' empowerment and self-determination must be fundamental to the research;

(b) Research should not be undertaken if it conflicts with the rights, wishes or freedom of the people to be researched;

(c) Indigenous peoples have distinctive languages, customs, spirituality, perspectives and understandings, deriving from their cultures and histories. Research that has indigenous experience as its subject matter must reflect those perspectives and understandings;

(d) Research must be undertaken in a manner that respects indigenous peoples' cultures, languages, knowledge, spirituality and values;

(e) Much of indigenous peoples' knowledge is transmitted orally and should be accorded equal status with documented and other knowledge sources;

(f) What tangible and intangible items constitute the heritage of a particular indigenous people must be decided by the people themselves;

(g) All researchers must respect indigenous peoples' privacy, cultural integrity and right to control their own heritage.

9. The above principles should guide any research and are of critical concern for all those engaged in education and research with indigenous people worldwide. This, we believe, needs to be addressed at international forums on indigenous people and within all systems of higher education.

TERRALINGUA

[Original: English]
[15 May 1998]

Linguistic human rights in education

1. Terralingua is an international non-governmental organization dedicated to supporting the perpetuation and continued development of the world's linguistic diversity, and exploring the connections between linguistic, cultural and biological diversity. In Terralingua's view, there are a number of basic concepts related to indigenous languages which should be considered.

2. Indigenous peoples represent around 4 per cent of the world's population, but control or manage almost 20 per cent of the surface of the earth and speak at least 60 per cent of the world's languages. The fate of the lands, languages and cultures of indigenous peoples is decisive for the

maintenance of biodiversity and linguistic and cultural diversity. All three are correlated, maybe also causally connected through co-evolution, and all three are seriously threatened.

3. Linguistic and cultural diversity may be eroding even more rapidly than biological diversity. Languages, the carriers of culture, are today disappearing at a much faster pace than ever before, mostly as a result of linguistic genocide. The main agents of linguistic and cultural genocide today are mass media and formal schooling, along with market and other forces which shape these and other opportunities for the use of indigenous languages outside the home. Therefore, linguistic and cultural human rights in education for indigenous peoples are crucial for the survival of indigenous languages and cultures and for the future of the planet.

4. The formal schooling of indigenous children is today conducted in most cases through the medium of a dominant language, not through the children's own language. Worldwide, the bulk of those indigenous children who are in schools are judged to have "failed" to achieve, and often are pushed out of the educational system early. Later on, they are commonly overrepresented in figures for unemployment, youth criminality and other statistics that portray them as "deficient" or "deviant".

5. This "failure" results, in most cases, from the education of indigenous children being organized in ways that contradict sound scientific evidence. This evidence indicates that mother-tongue-medium education for indigenous children, with good teaching of the dominant language as a second language, is the most secure way to achieve multilingualism without loss of the mother tongue. Despite the availability of this evidence, the persisting choice of an inappropriate language medium of education is the main pedagogical reason for "illiteracy" in the world. Indigenous parents are routinely told that their children will learn the dominant language better (and thus perform better in school) by being exposed to it as early and as much as possible, even at the cost of sacrificing their own language. Moreover, most "development aid" for indigenous and minority education supports these scientifically unsound educational choices.

6. Therefore, the promotion of linguistic human rights in education must take place at two levels. People must have rights, and they must have access to the knowledge needed for making informed educational choices.

7. Terralingua recommends that indigenous children be granted basic linguistic human rights in education. Indigenous peoples have the right to exist and to reproduce themselves as such, with their own languages and cultures. This is a self-evident, fundamental collective human right, as contained in the draft declaration of the rights of indigenous peoples. For indigenous peoples, self-determination includes the right to decide about their education. At the individual level, everyone has the right to identify with, to maintain and to fully develop one's mother tongue(s) (the language(s) a person has learned first in life and/or identifies with). This is a self-evident, fundamental individual linguistic human right. Necessary individual linguistic human rights have to do with access to the mother tongue(s) and an official language, the relationship between them, and language-related access to formal primary education. Thus, a universal

declaration of linguistic human rights should guarantee, at an individual level, in relation to the mother tongue(s) that everybody can: (a) identify with their mother tongue(s) and have this identification accepted and respected by others; (b) learn the mother tongue(s) fully, orally (when physiologically possible) and in writing. In most cases, this requires for indigenous and minority children to be educated through the medium of their mother tongue(s); (c) use the mother tongue(s) in official situations (including schools).

8. Terralingua also recommends that everybody whose mother tongue is not an official language in the country where they are resident become bilingual (or multilingual, if they have more than one mother tongue) in the mother tongue(s) and (one of) the official language(s) (according to their own choice).

9. Terralingua recommends further that any change of mother tongue be voluntary, not imposed (i.e., it includes knowledge of long-term consequences and is not due to enforced language shift), and that everybody be able to profit from education, regardless of what their mother tongue(s) is/are.

10. Some recent human rights instruments can be drawn on to support linguistic human rights in education according to these principles. In addition to those specifically geared towards indigenous peoples, of particular relevance are the Hague recommendations regarding the education rights of national minorities and explanatory note (October 1996), issued by the Foundation on Inter-Ethnic Relations for the OSCE (Organization for Security and Cooperation in Europe) High Commissioner on National Minorities, Mr. Max van der Stoel. These recommendations, applicable to indigenous children as well, are built on scientifically sound pedagogical principles and on the provisions of international human rights law concerning minority education.

11. Indigenous peoples need to know enough about the long-term consequences of educational choices, especially choice of medium of education, in order to be able to make free, informed decisions. Indigenous peoples' ability to make free, informed educational choices is mainly hampered by ideologies that stigmatize and devalue these groups' languages, cultures, norms, traditions, institutions, level of development, observance of human rights, etc., while glorifying those of the majority/dominant group. These ideologies rationalize and legitimate the unequal relationship between the dominant and the dominated, by portraying the actions of the dominant group as always functional, as well as beneficial to the subordinated groups, who are instead portrayed as "primitive", "backward", not able to adapt to present-day technological information society. Such ideologies also diagnose the problems indigenous children face at school as due to the children's, their parents' and their groups' "deficient characteristics". Attributed deficiencies on which school failure is blamed include second-language (L2)-related deficiencies (the children do not know the dominant language well enough); cultural deficiencies (the parents' culture is not conducive to supporting school achievement); social deficiencies (the parents represent low-ranking social groups); and even first-language (L1)-related deficiencies (the children - and parents - do not know their own language well enough, and this leaves the children without a proper base for learning the dominant language).

The "remedies" adopted by most majority educational systems have been geared towards "helping" children to overcome "their deficiencies", in particular by increasing the focus on the teaching of the dominant language and dominant cultural norms, through submersion programmes or, at best, early-exit bilingual programmes, in which the mother tongue is used initially as the medium of education, until the children are supposed to "know" enough of the dominant language in order for a complete transition to it to take place. These "remedies", based on a wrong diagnosis of the problem, try to "remedy" the child, parents, and the indigenous community, instead of changing the educational system. The evidence shows that such measures do not work. Furthermore, they do not respect linguistic human rights in education.

12. Education leading to high levels of multilingualism and school achievement and which respect linguistic human rights in education would conform to the following principles: (a) expect all children, not only indigenous children, to become high-level bilinguals; (b) expect all teachers to be bi- or multilingual, so that they can be culturally appropriate models for the children and adequately support them in language learning; (c) equalize the status of the mother tongues of all children in the organization of schooling, in the role of the languages in class schedules and in higher education, in testing and evaluation, in marks given for the languages, in use in school administration, meetings and assemblies, as well as in the status and salaries of the teachers, in their working conditions and career patterns; (d) teach all children, through grade 12, both the dominant and the indigenous languages as compulsory subjects (language learning); (e) use as the main language of instruction (content learning), for at least the first eight years, the language which is least likely to be used in official domains outside school. For indigenous children, this means being taught all subjects in their own mother tongue (L1) during this phase; for dominant group children, it can mean instruction in an indigenous language; (f) use both languages (L1 and L2) as media of education in some phase of the children's education (for indigenous children, at least some subjects must be taught through L1 all the way through grade 12, while other subjects begin to be taught through L2 after the initial phase of instruction in L1 only); (g) adopt systems that promote equality in children's knowledge of the language(s) of instruction: mother-tongue-medium education (where everybody in the class knows the language); immersion programmes for majorities learning through the medium of an indigenous language, as well as indigenous children first learning L2 as a subject, and later learning content through L2 (where everybody in the class is in the process of learning the language); "two-way" programmes (where half the class are indigenous children with the same mother tongue and half are majority children, taught together by a fully bilingual teacher, initially through the medium of the indigenous language and later through both, with both languages taught as subjects to both groups).

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PRINCIPAL THEME: INDIGENOUS PEOPLES - EDUCATION AND LANGUAGE

Note by the secretariat

1. At its fifteenth session, the Working Group on Indigenous Populations decided to highlight the issue of "indigenous peoples: education and language" at its sixteenth session. In this regard it decided to encourage the United Nations Educational, Scientific and Cultural Organization to make its contribution both substantively and through the participation of the relevant experts and staff. The Sub-Commission on Prevention of Discrimination and Protection of Minorities, in its resolution 1997/14, endorsed the decision of the Working Group. In its resolution 1998/13, the Commission on Human Rights also welcomed the decision of the Working Group to highlight the issue of "indigenous peoples: education and language".

2. In a letter dated 15 April 1998, the Chairperson-Rapporteur of the Working Group, Mrs. Erica-Irene Daes, wrote to the Director-General of UNESCO informing him of the theme of the sixteenth session of the Working Group and inviting his organization to make an appropriate contribution to the discussions. The Office of the United Nations High Commissioner for Human Rights, in a note dated 18 May 1998, transmitted a summary of the decisions of the Commission on Human Rights relating to indigenous issues to Governments, intergovernmental organizations and organizations of indigenous peoples, including the information that "indigenous peoples: education and language" would be highlighted by the Working Group at its session in July 1998.

3. The purpose of the present note is to identify possible themes related to the topic under discussion and to encourage a technical and forward-looking exchange of views and information which would help the international community to take practical steps to assist States and indigenous peoples achieve improvements in educational opportunity and access and contribute to the protection of indigenous languages. Previous experience of the Working Group suggests that a debate focused on a specific issue related to the rights of indigenous peoples helps participants to understand the broader dimensions of a question and learn from developments in countries other than their own. In particular, it is to be hoped that indigenous and non-indigenous teachers and educational practitioners working with indigenous peoples, including administrators of educational programmes, researchers and other experts, can find stimulation and encouragement from sharing information about their different practical experiences.

Improving educational opportunity

4. One critical issue which confronts some indigenous peoples is their limited access to mainstream education at all levels - primary and secondary schooling, university and tertiary education as well as vocational training. In general, statistics relating to indigenous education indicate a proportionately lower level of access, attendance and achievement than the wider society. The greater difficulties experienced by indigenous people in obtaining formal academic qualifications, and the more restricted opportunities for education generally, impact upon employment and income as well as on the broader participation of indigenous persons in civil society. Education is recognized as a means of breaking the cycle of poverty, disadvantage and exploitation in which some indigenous communities find themselves entrapped.

5. Indigenous peoples, Governments and independent researchers have identified some of the underlying causes of educational disadvantage of indigenous peoples and looked at ways of addressing them. In the last two decades or more national educational policies and indigenous initiatives in some countries have contributed towards dramatic improvements in indigenous education through scholarships, special schools for indigenous children, the development of more culturally appropriate educational methods, and programmes for distance learning.

6. Under this question, the following possible themes are proposed:

(a) Causes of educational disadvantage;

(b) Special measures of States to improve access of indigenous children to education;

(c) Culturally appropriate education for indigenous peoples;

(d) Experiences of distance learning for indigenous peoples in remote areas;

(e) Continuous and adult learning for indigenous peoples.

Strengthening indigenous educational establishments and languages

7. Indigenous peoples have criticized and condemned past practices of States by which indigenous children were separated from their parents and sent to residential schools. Criticisms have also been levelled against religious schools established in more isolated indigenous communities whose intent was to undermine indigenous cultures, customs and beliefs. There is now widespread recognition that such practices constituted a discriminatory policy aimed at diminishing and destroying indigenous cultures and societies. Indigenous peoples have also expressed their concern about school curricula and classroom practices which undermine indigenous value systems and self-esteem.

8. In their efforts to protect their culture, reinvigorate their languages and ensure the transmission of values from the older generation to the younger, indigenous peoples have established their own schools, colleges, and language-teaching courses. Such educational initiatives provide opportunities for indigenous people to have courses in their own languages and in an atmosphere which takes account of their own customs. States have introduced changes in their educational policies to encourage and provide support for indigenous-run schools. In many countries, these developments have led to a rise in educational performance and a resurgence in the use and interest in indigenous languages. Furthermore, there are now a growing number of university departments focusing on indigenous issues and indigenous-controlled research and adult learning institutes.

9. Under this question, the following possible themes are proposed:

(a) Experiences of bilingual teaching;

(b) Indigenous-run schools and colleges;

(c) Experiences of reviving and strengthening indigenous languages;

(d) Special measures taken by States to support indigenous involvement in and control of their own educational establishments and curricula.

Reflecting indigenous heritage in national curricula

10. It is recognized that the histories and cultures of indigenous peoples have often been portrayed in an inaccurate or derogatory way in public documents and some educational materials. The effect of such literature led to misunderstandings about indigenous cultures and misinterpretations of history, thereby contributing to prejudice in the wider society. Efforts are now being made to ensure that educational material reflects in a balanced way the pluricultural character of most modern States and their histories. The draft United Nations declaration on the rights of indigenous peoples presently under review by a working group of the Commission on Human Rights contains in article 16 a specific provision to this effect.

11. In this respect, the cultures and histories of indigenous peoples are today more accurately reflected in educational materials and public information. Indigenous and non-indigenous experts are involved in the

development of relevant documentation and teacher training in countries where indigenous peoples live increasingly includes in some part of the programme the diversity of cultures, in particular indigenous cultures, that the teacher will meet in the classroom. Indigenous peoples have called for a greater involvement in setting the framework for research and university-level education since until comparatively recently there was little opportunity for indigenous students to follow courses of study on their own sciences, knowledge systems and cultures. Furthermore, non-indigenous students were not offered any possibility to follow courses on contemporary indigenous issues. A workshop for research and higher education institutions focusing on indigenous issues is due to be organized by the Office of the High Commissioner for Human Rights, as requested by the General Assembly in its resolution 52/108, in late 1998/early 1999.

12. Under this question the following possible themes are proposed:

(a) Teaching materials reflecting indigenous cultures and perspectives;

(b) Sensitizing teacher training to indigenous peoples;

(c) Special measures taken by States to develop curricula and education reflecting indigenous cultures;

(d) Elements for the discussion at the workshop for research and higher education institutes focusing on indigenous issues as proposed by the General Assembly in its resolution 52/108.

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Sub-Commission on Prevention of
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Working Group on Indigenous Populations
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Item 6 of the provisional agenda

STANDARD-SETTING ACTIVITIES: EVOLUTION OF STANDARDS CONCERNING THE RIGHTS OF INDIGENOUS PEOPLES

Human genome diversity research and indigenous peoples

Note by the Secretariat

Introduction

1. Modern science has developed to the point that scientists are now seeking to trace history and cure disease by investigating human, animal and plant genes. While this practice has been occurring for some time using plant and animal genes, it is only recently that human genes have been used in research. Therefore, the discussion of the ethical and legal issues arising from the use of human genes for research is also relatively new. A parallel development in scientific research generally is the steady move from State-sponsored to privately funded research, and the inevitable influence of the profit motive in this field. As a consequence, many major projects in scientific research, including in the field of human genome research, are conducted by large pharmaceutical companies, not universities or government research institutes.

2. These rapid changes have left some observers feeling that the ethical and legal implications of human genome research have not been taken seriously by those who undertake and benefit from such work. Such implications exist at every stage of the work, including the actual creation of research projects to study human genome material, the collection of samples, the subsequent research and possible manipulation of genes, and the products and results stemming from the research undertaken.

3. Indigenous peoples have come into contact with human genome research predominantly as subjects of research in the Human Genome Diversity Project outlined below. The discussion of the ethics and legality of such research in the context of indigenous peoples should focus on issues of consent to becoming subjects in the HGDP, and of their possible rights to enjoy the benefits of the research, financial, medical and anthropological. The present note does not attempt to judge the Human Genome Diversity Project, but rather provides a starting point for the discussion of the complex and emotionally charged issues surrounding the involvement of indigenous peoples in the HGDP. In the light of resolution 1997/15 of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, which recognizes the need for systematic analysis of this issue, and given the growing debate and apparent mistrust that prevails, it has been thought useful to provide some preliminary information relating to the research in this area.

The collection of human genome samples

4. A genome is all the DNA in an organism, including its genes. Genes carry information for the making of all the proteins required by the organism. The proteins determine how the organism looks, its resistance to disease, and many other characteristics. DNA is made up of four similar chemicals, called bases, and given the codes A, T, C and G for identification. The bases are repeated millions or billions of times throughout a genome. The variety of the combinations of these four bases are the foundation of life's diversity.

5. Before genes were able to be isolated in human tissue or blood, studies were conducted on proteins. There was, however, limited scope for their use in research, as proteins do not vary extensively from one person to the other. During the 1980s the science of molecular genetics matured into the study of stretches of human DNA that do not encode proteins. This led to the discovery of many polymorphisms - DNA sequences that vary from one person to the next. There are thousands of polymorphisms and this diversity allows the identification of previously undetected genetic variation within and between populations.

The Human Genome Diversity Project

6. A major project in human genome research is the creation of an international human gene pool by the Human Genome Diversity Project (HGDP). The HGDP Project aims to collect DNA samples from over 500 linguistically distinct groups across the globe (Nature, vol. 381, 2 May 1996). These groups are to be selected from a possible 7,000 populations worldwide (with Europe being considered separately), determined by a group of anthropologists to be "worthy of study" (Science, vol. 258, 20 November 1992, pp. 1300-1301). The practical working of the Project requires blood or tissue samples from at least 25 individuals from each population, who have given prior "informed consent" at an individual and/or community level.

7. The groups considered "worthy of study" are determined by a number of factors. Isolated population groups are highly valued as they can provide genetic information unique to that group and not "blurred" by mixing with other groups. Many indigenous peoples live in very isolated communities, have therefore kept their bloodlines "pure", and so are highly valued as subjects of the HGDP (Nature, op. cit.). In addition, it is perceived that a number of

these population groups will not exist for much longer because of the trend towards mixing with other population groups or by total extinction. The Project organizers have emphasized the need for haste in order to record the DNA of these groups before they cease to exist: "(e)veryone agreed the highest priority should go to unique, historically vital populations that are in danger of dying out or being assimilated" (Science, op. cit.).

The predicted benefits of the Human Genome Diversity Project

8. Supporters of the HGDP have argued that the Project will have benefits for humanity and for knowledge generally, and more specifically for the participant groups. It is reasonable to state that most supporters prioritize the former. It has been suggested that the HGDP will benefit four major areas of research and hence contribute to the wealth of knowledge of all humankind: the study of human origins and prehistory; the study of social structure, for example mating and marriage patterns; the study of adaptation and disease, for example anatomy, physiology and disease susceptibility; and forensic anthropology (group identification techniques). The creator of the HGDP is Mr. Luigi Luca Cavalli-Sforza, a population geneticist and professor emeritus at Stanford University in California. He argues that the HGDP would enable the creation of a wealth of knowledge of the history of modern ethnic differentiation and human variation. He also emphasizes the identification of links between language and other cultural characteristics and the distribution of genetic profiles throughout the world.

9. More specifically addressing the plight of indigenous peoples and how the Project can help them, Mr. Cavalli-Sforza stated in a paper prepared in 1993 for the United States Senate Committee on Government Affairs regarding the Project that

> "The Project's investigations may make the burdens borne by particular populations public knowledge. The Project can also generate greater public knowledge and interest in cultural diversity and the desirability of maintaining it. It would of course be impossible to reach all populations in need in the course of the Project; there are about 5,000 different populations in the world, based on the count of different languages in existence, and the Project can reach about 10 per cent of them."

In addition, the Project's North American Committee explained in 1994:

> "In the long run, populations that participate in the Project will learn more about their history and origins. Of course, some populations, in both the developed and the developing worlds, may not be very interested in what science deduces about these matters, being content with their own explanations. Nevertheless, even populations that do not seek scientific explanations for their origins may reap long-term benefits from the discovery of useful medical information about their susceptibility to, or treatments for, disease. Because genetic data can also be recovered from bones, teeth, and soft tissues, some populations may also wish to use this approach to help them identify recent or ancient remains that are found in or near their lands."

Concerns raised regarding the Human Genome Diversity Project

10. There has been strongly worded opposition by indigenous representatives and others to the collection of human genome samples from indigenous peoples. The American Indian Law Alliance and other opponents call the HGDP the "Vampire Project", referring to the taking of blood and skin samples from living humans. While all participants in the Project may have concerns, for example ensuring fully informed consent and regarding property rights of information gathered. However, these and other issues surrounding this project appear to affect indigenous groups in a unique manner, for reasons which may include traditional belief structures or a perceived lack of bargaining power. Difficulties with the Project specific to indigenous peoples include the attitude of the Project to indigenous peoples, the perceived violation of their cultural and religious values by interference with the human body, the possible effects the information gained may have for a sampled community, the problems of gaining fully informed consent for the collection of samples from the appropriate power in the community (which may not be just the individual participant), and the participant's property rights over samples and the products of research.

11. The human genome samples are taken from individuals by way of blood donation or the removal of other tissue such as hair or the scraping of skin from inside the cheek. This removal of blood and human tissue is highly offensive to some indigenous cultures in a way not understood by Western science. In addition, the Western scientific practice of trying to divide nature into its smallest elements is the antithesis of indigenous respect for nature as a sacred whole. This is expressed in the Declaration of Indigenous People of the Western Hemisphere Regarding the Human Genome Diversity Project adopted in Phoenix, Arizona, in 1995, which opposes the Project and criticizes efforts of Western science "to negate the complexity of any life form by isolating and reducing it to its minute parts ... and [thereby] alter its relationship to the natural order".

12. Some indigenous peoples see the Project as a new form of colonialism, with sinister overtones; the Western world has taken their land and animals and destroyed their culture, and now it wants to take what is scientifically valuable of the people themselves, and leave them to die out. Indigenous groups have also taken great offence at comments made in the context of the HGDP that their DNA data must be collected before they "disappear", either by extinction or by mixing with other population groups.

13. It is also claimed that the Project is potentially racist as it is based on outmoded notions of race and that human groups may be defined by genetic characteristics but that these vary from group to group in a distinctive manner. At the very least, it is feared that the information will be hijacked for political purposes to support arguments that certain population groups are genetically superior or inferior. A report entitled "Bioethics and human population genetic research" submitted to the third session of the UNESCO International Bioethics Committee in November 1996 pointed out that there is greater diversity within populations than between them and that population geneticists note that population genetics offers no scientific basis for the belief that certain races (however defined) are superior to other races. But,

the report notes, it is of concern that some scientists involved in the Project do not acknowledge that possible racist implications should be a consideration in their work.

14. The Project organizers emphasize that informed consent will be obtained from participants in the Project. Exactly what "informed consent" is and how it is best secured are difficult issues when dealing with isolated communities who have no or little Western scientific knowledge. Informed consent implies that the Project participants are fully informed, and fully understand why the samples are being taken, their rights to samples and the knowledge gained from the study, and the opportunities for financial compensation for the taking of samples and results stemming from them.

15. To explain the extraction of DNA from blood and human tissue and the lessons that can be learned from the results of this work are difficult concepts even for the well educated; to explain them fully to isolated rural peoples may be expected to be even more difficult. Considerable reliance is placed on anthropologists who have had connections with the target population to cross this divide. However, some indigenous representatives are concerned that anthropologists themselves are becoming too involved with "gene hunting" and not enough with the cultural and social aspects of the people they study.

16. Another major difficulty for scientists is to obtain consent for sampling from the correct authority. Understandably, for the scientists, permission is most easily sought from an individual, possibly with the incentive of a medical check-up, or perhaps even with some monetary compensation. Many indigenous communities have a communal or hierarchical decision-making structure that overshadows an individual's right to give consent, particularly when the consent has implications for the entire community. In addition, it is arguably not satisfactory for consent to be given by a community leader without the fully informed consent of the individual concerned. Ironically, the characteristics of the target groups that make them scientifically very appealing also make it extremely difficult to deal with the cultural implications of the Project for each of the groups.

17. Financial or medical benefits can be a strong incentive for participation in the Project. The IBC report, however, noted the ethical problems of payment and stated that no undue compensation should be offered to ensure participation in sampling, which may be extremely difficult to control given the one-sided power relationship in the poorer areas of the world. The financial benefit should be seen in terms of communities, not individuals. It is suggested that other benefits can be passed on to the participants, for example, medical treatment and the anthropological and medical results of the research. There are possible difficulties that arise from these suggestions. Some see the provision of medical treatment in return for samples as merely a smokescreen that hides the lack of full consent. The returning to the participatory communities of the results derived may provide knowledge that is in conflict with a community's traditional beliefs relating, for example, to the origin of its people, which indigenous peoples may not want to know or to be known by others.

18. The HGDP is intended to be a widely accessible gene pool for general use, and would include important information regarding the origins of the samples. Indigenous groups have called for access to such information to be

limited in order to prevent the information from being used to the detriment of the group concerned. For example, if a group is found to have a genetically high risk of contracting a certain disease and an insurance company were to discover this, members of that community might be denied insurance coverage by that company. At the extreme, concerns have also been expressed that it is possible that this knowledge could be used in developing biological weapons targeted at the particular indigenous groups.

19. Research on human genome samples has led to advancements in the treatment of many diseases, including cancer and AIDS. Understandably, this knowledge is extremely valuable in financial terms and the patenting of human cell lines has become big business. The owner of a patent has legal rights over the subject of the patent and therefore to any profits that may be made therefrom. Opponents of patenting of human genes argue that the identification of a human genome is a discovery, not an invention, and is therefore not liable for patenting, as is the case for laws of nature which are deemed to be a discovery of something already in existence and therefore not invented.

20. Patenting of human genome material, however, does occur and has been accepted by courts in some countries. The ground-breaking case in the United States of America, Moore v. Regents of the University of California, determined that once human tissue had been taken with the consent of the person, he or she no longer had rights to that material and therefore could not gain financially from the research. In 1985, a United States businessman, Mr. John Moore, filed a lawsuit claiming that his blood cells were misappropriated while he was undergoing treatment for leukaemia at the University of California. During this treatment, Mr. Moore's doctor developed a cell line that was used in fighting cancer. The University filed a patent claim on the cell line and developed pharmaceuticals commercially using the cell line. The Supreme Court of California ruled that Mr. Moore did not have property rights to the cells taken from his body, and therefore had no claim to profits derived from research conducted on them.

21. Patents have also been filed on the cells of indigenous peoples. In 1993, the United States Secretary of Commerce filed a patent on the cell line of a 26-year-old indigenous Guaymi woman from Panama. The Guaymi people were found to have a particular virus and antibodies that are relevant to research on AIDS and cancer research. The patent claim was withdrawn after a public outcry, but since then United States authorities have had more success. For example, on 14 March 1995, an indigenous man of the Hagahai people of Papua New Guinea's remote highlands, had his DNA patented by the United States National Institute of Health. The patent covers a cell line containing unmodified Hagahai DNA. Between 1981 and 1995 a total of 1,175 patents for human DNA sequences were granted worldwide. More than three quarters of these patents are privately owned, most by companies based in Japan and the United States (Nature, vol. 380, 4 April 1996, pp. 387-388).

22. There are two primary arguments against the patenting of human materials. The first is that the patenting of any life - human, animal or plant - is objectionable in many cultures, for a variety of reasons including the respect for nature, religious beliefs, and the attitude that "some things are just not for sale". For many indigenous and other communities, the gift of blood is sacred and the involvement of profit-oriented corporations in this

transaction is seen as the commodification of humans and their bodies. The second is that in practice, the person who is the source of the material is unlikely to receive the financial benefits deriving from the patent, and any such benefit would rely on the generosity of the patent owner, not on any legal right. While the latter issue affects any participating individual and community, indigenous populations arguably have minimal access to the legal advice and political power necessary to secure an outcome satisfactory to them.

23. The organizers of the HGDP emphasize that the Project is not about making money but expanding knowledge, and that they do not intend to patent any samples or resultant products. They also state that any financial benefits should be returned to the sample populations. However, the aim of the Project is to develop a gene bank that is accessible to scientists generally. Even if the HGDP scientists are willing to recognize the rights of the sample populations, the scientists who later use the gene bank may not agree. Indeed, with the bulk of existing patents in private hands, commercial considerations are paramount in scientific research using human genome material.

24. Even if some form of compensation of participants is envisaged, it creates more difficult issues, particularly regarding the distribution of rights between the individual and the community. To whom should the benefits flow? In Western legal systems, legal rights are held by "legal persons" - an individual or registered company. The IBC report poses the question, "Can one individual sign away commercial rewards to future research knowledge for the population to which they belong?" If the answer is no, then how would funds be given to the community? A large amount of money injected into a relatively poor community may provoke irreparable damage to its traditional culture. The danger of commodification of humans may be enhanced, rather than slowed, by the payment of royalties. Conversely, to deprive the community of such funds is to ignore their essential contribution to the Project.

25. Compromises have been suggested, for example, creating a trust fund to be administered by an independent body for the benefit of the populations concerned. But this is no answer for those who consider that it is their right to maintain legal control of the products developed from or with the assistance of their genes.

Addressing the ethical and legal issues

26. Many interest groups, research bodies, legislatures and a number of international organizations have raised the issue of possible ethical and legal implications in the collection of human genome material. A number of indigenous organizations and representatives have called for the outright banning of human genome collection. For example, in February 1995 a forum of indigenous peoples of Asia issued a statement to the European Parliament in which they strongly opposed the HGDP and demanded that it be stopped. The Beijing Declaration of Indigenous Women formulated at the Fourth World Conference on Women in 1995 demanded that the Project be condemned and stopped, as have other communities, such as the group of indigenous organizations that met at the Ukupseni community in Kuna Yala, Panama in November 1997 and also adopted a declaration on the Project. In the Declaration of Indigenous Peoples of the Western Hemisphere Regarding the

Human Genome Diversity Project, 17 indigenous peoples' organizations in the Americas demanded that the HGDP and any related programmes be stopped, and that the United Nations and other international organizations work with indigenous peoples to protect all life forms from genetic manipulation and destruction.

27. The Rural Advancement Foundation International (RAFI), a non-governmental organization that has been instrumental in the protests against the HGDP and active in the Hagahai patent case mentioned above, is seeking stronger restrictions on the patenting of human genetic material in the intellectual property provisions of the General Agreement on Tariffs and Trade. RAFI has called for the recognition of two systems of values, the indigenous system, being the "cooperative innovation system", and that of modern science, the "institutional innovation system", and for the recognition of the contribution and value of the former to the world's food supplies, farming systems and medicinal needs.

28. There are a number of international human rights instruments that may have some bearing on this issue. The Universal Declaration of Human Rights, in article 3 states, "Everyone has the right to life, liberty and security of person", and in article 5, "No one shall be subject to torture or to cruel, inhuman or degrading treatment or punishment". Article 12 states, "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks on his honour and reputation. Everyone has the right to the protection of the law against such interference and attacks." The International Covenant on Civil and Political Rights, in article 17, echoes this right, though referring to "unlawful" attacks. Article 15 (1) of the International Covenant on Economic, Social and Cultural Rights states that everyone has the right:

"(a) To take part in cultural life;

"(b) To enjoy the benefits of scientific progress and its applications;

"(c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author."

The Proclamation of Tehran, in paragraph 18, states, "While recent scientific discoveries and technological advances have opened vast prospects for economic, social and cultural progress, such developments may nevertheless endanger the rights and freedoms of individuals and will require continuing attention." The UNESCO Declaration on Race and Racial Prejudice, article 1, states:

"1. All human beings belong to a single species and are descended from a common stock. They are born in equal dignity and rights and all form an integral part of humanity.

"2. All individuals and groups have the right to be different, to consider themselves as different and to be regarded as such. However, the diversity of life styles and the right to be different may not, in any circumstances, serve as a pretext for racial prejudice; they may not

justify either in law or in fact any discriminatory practice whatsoever, nor provide a ground for the policy of apartheid, which is the extreme form of racism.

"3. Identity of origin in no way affects the facts that human beings can and may live differently, nor does it preclude the existence of differences based on cultural, environmental and historical diversity nor the right to maintain cultural identity.

"4. All peoples of the world possess equal facilities for attaining the highest level in intellectual, technical, social, economic, cultural and political development.

"5. The differences between the achievements of the different peoples are entirely attributable to geographical, historical, political, economic, social and cultural factors. Such differences can in no case serve as a pretext for any rank-ordered classification of nations or peoples."

29. The IBC report referred to above was followed by the *Universal Declaration on the Human Genome and Human Rights*, adopted unanimously at the twenty-ninth session of the UNESCO General Conference on 11 November 1997. The Declaration addresses many of the concerns of indigenous people, while also acknowledging the benefit to humankind of valuable discoveries that can come from study of the human gene. Therefore, it does not call for the abolition of the collection of human genome samples, but rather seeks to set international standards ensuring the human rights of participants. The United Nations Commission on Human Rights at its forty-third session adopted resolution 1997/71 entitled "Human rights and bioethics" in which it referred to the need to preserve the dignity and integrity of the human being and to ensure that scientific progress benefited individuals and developed in a manner respectful of fundamental human rights.

30. Other organizations have also been involved in the setting of standards for this work. The Human Genome Organization (HUGO), the international coordinating body for human genetics studies endorsed in March 1996 a Statement on the Principal Conduct of Genetic Research drawn up by its Ethical, Legal and Social Issues Committee. The Committee based its recommendations on four principles: recognition that the human genome is part of the common heritage of humanity; adherence to the international norms of human rights; respect for the values, traditions, culture and integrity of participants; and acceptance and upholding of human dignity and freedom. The Committee recommended that "undue inducement" through compensation for individuals, families and population groups taking part in gene mapping should be prohibited, but that agreements might be made, inter alia, for the provision of health care or information structures or for the possible use of a percentage of any royalties for humanitarian purposes.

31. The recommendations also referred to the need to obtain informed consent "free from coercion by scientific, medical, or other authorities". Such consent could be "individual, familial, or at the level of communities and populations". This question is seen as problematic in some quarters as it implies that scientists may not need to gain individual consent.

32. HUGO's Intellectual Property Rights Committee prepared a Statement on Patenting Issues Related to Early Release of Raw Sequence Data in late 1997, approved by the Council of HUGO, in which the organization reaffirmed its opposition to the patenting of "short sequences from randomly isolated portions of genes encoding proteins of uncertain functions", but clarifying that it did not oppose the patenting of "useful benefits derived from genetic information".

33. The 93rd Inter-Parliamentary Conference adopted by consensus a resolution on bioethics in which it stressed the urgent need, inter alia, to develop international principles which respect cultural diversity, prohibit financial gain from human products and ban the patenting of human genes. The Organization of African Unity, at its 32nd Ordinary Session, pledged to promote respect for the rights of individuals in relation to this issue and to encourage member States to legislate on and create consultative bodies to monitor this question. The European Convention on Human Rights and Biomedicine, in article 21, states "The human body and its parts shall not, as such, give rise to financial gain" (this does not include hair and nails, sources of DNA, as their collection is deemed not to be an affront to human dignity). The IBC report notes that this may be considered a Western judgement.

34. Individual countries have also taken steps to address these issues. India has been developing legislation to ensure that those providing DNA samples are entitled to a share of royalties from their use. There is a possibility that some Pacific nations may ask the International Court of Justice for an Advisory Opinion on the morality of patents on human genes and are developing a "Lifeforms Patent-Free Pacific Treaty". Some other countries have legislation dealing with ethics in medicine.

35. Not all States are supportive of the banning of patenting of human products. During the 1992 Earth Summit in Rio de Janeiro, the United States, one of the largest partners in the HGDP Project, expressed the view that genes of plants and animals belong to a common international heritage, and accordingly are not owned by their keepers. The implications of this view are that any financial benefits gained from these items will go to those who manipulate the genetic repository to commercial advantage. Many people from developing counties, where most of the genetic diversity is found, reject this as an exclusively first world view. Recent advice issued by the Patent and Trademark Office of the United States Department of Commerce, however, indicates a possible change in attitude. The Office warns that, "inventions directed to human/non-human chimera could, under certain circumstances, not be patentable because, among other things, they would fail to meet the public policy and morality aspects of the utility requirement" of patent law, as courts have interpreted the utility requirement to exclude inventions deemed to be "injurious to the well-being, good policy, or good morals of society". (Lowell v. Lewis, Fed. Cas. No. 8568 (C.C. Mass. 1817), quoted in Tool-O-Matic Inc. v. Proma Product - und Marketing Gesellschaft M.b.H., 945 F.2d 1546, 1552, 20 USPQ2d 1332, 1338 (Fed. Cir. 1991)).

The future of the HGDP

36. Unlike statements of many indigenous representatives, neither the IBC report nor the UNESCO Declaration call for Projects such as the HGDP

to be abandoned. Rather, they emphasize the need to consider basic human rights in population genetics, and address a number of the concerns with suggestions on how problems can be, at least to some extent, overcome. For example, they call for indigenous groups and community representatives to be included in discussions of the Project and urge researchers to consider the history of the group that they plan to include in their research, taking into account matters not only of scientific interest, but also the ethical, social and ideological impact on the group of the research.

37. The IBC report emphasizes the need for "informed consent" by defining certain minimum information, in the subject's own language, before asking someone to consent to any sampling or treatment, including a basic description of the procedure and a description of the risks and benefits of the resultant information. The report notes, however, that the likelihood of obtaining truly informed consent is virtually impossible, particularly as it can never be ascertained for certain that information provided to people is completely understood. The report therefore concludes that the question is not so much one of "informed consent" as of ensuring that scientists properly inform potential participants, taking into consideration the cultural and religious needs and aspirations of the community.

38. The report also addresses the issue of collective consent to be the subject of study. Government approval needs to be secured in the first instance, and this needs to be complemented by consent from the individuals and the local groups/communities selected for the study, whether the consent is obtained directly or through formal/informal leadership, group representative or trusted intermediaries. Consent would need to be obtained from the most appropriate persons, taking into account the group's social structure, values, laws, goals and aspirations, and it must be ensured that the actual physical removal of samples of saliva, skin, hair, or blood do not violate cultural norms. The form in which consent is given will need to be discussed and agreed upon by each community.

Conclusion

39. The Human Genome Diversity Project continues, despite the objections of many indigenous peoples. It is arguable that there is a developing awareness of and sensitivity to the ethical and legal issues surrounding the collection of human genome. Many projects in this area now have an ethical, legal and social implications (ELSI) component, ensuring that a certain percentage of the Project budget is devoted to issues such as informed consent, privacy and education. It is possible that some of the concerns of indigenous peoples can be addressed through international and local desire to improve consultation with indigenous peoples and through changes in patent law. Some concerns of indigenous peoples, however, cannot be adequately addressed without a complete ban on projects such as the HGDP, and of the patenting of human genome materials.